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## Introduction: The Politics of Anonymity and Confidentiality

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It is a standard requirement of ethics committees that researchers address questions concerning anonymity and confidentiality. The conventional practice is to ensure that participants' names and identifying details are expunged from the public records of the research and that high levels of confidentiality of data be maintained in the research process. In this introduction, we outline how authors of chapters in this section ask questions concerning these imperatives, including circumstances in which participants actively want their identity revealed and their voice heard, or when anonymising might not be possible, or may further disadvantage marginalised populations.

Each chapter in this section draws on fieldwork research that required careful thought about participants' anonymity and confidentiality in relation to institutionally defined notions of harm. Naidu (2018, this section) reflects on negotiating anonymity in the process of publishing a clinical case study that included poetry written by the participant undergoing medical surgery, as well as a case of an HIV/AIDS home-based care volunteer group. Rice and Mykitiuk (2018, this section) consider the implications of working with non-normatively embodied and en-minded research participants who frequently experience remaining invisible. Similarly, Marx and Macleod (2018, this section) think through the

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tensions generated by the erasure that anonymity might enforce by providing an account of attempting to obtain approval for research proposals that involved female participants who had experienced intimate partner violence and queer-identifying participants in drag, respectively. Like Marx and Macleod, Ashdown et al. (2018, this section) situate their research in a critical framework by considering the implications of working in indigenous Māori communities for whom conventional notions of anonymity in research may contradict a larger political and cultural project of reclamation in a context marked by colonialism. In turn, Rucell (2018, this section) asks what the social implications are for concealing the identities of organisations that do harm to participants whom a researcher encounters and whether the commitment to anonymity and confidentiality in such cases may be considered equally unethical.

All the authors in this section recognise the importance of thinking carefully through questions of anonymity and confidentiality. They acknowledge that these standard measures are put in place in the name of protecting research participants, firstly, from potential harms that may accrue in having their identity revealed particularly if they disclose sensitive information and, secondly, in terms of their right to privacy. We begin, therefore, by outlining the purposes of anonymity and confidentiality as commonly seen in ethics protocols. We then explore the arguments made by authors that the automatic anonymising of data and the imposition of confidentiality can constrain ethical conduct. This coheres around two key observations: firstly, the virtual impossibility of completely concealing the identity of participants or organisations within particular kinds of research and, secondly, the dilemmas researchers face, particularly those engaged in critical and emancipatory research, when participants request that researchers reveal their identities. We then pose some of the questions that have arisen in relation to the assumption that researchers must maintain anonymity and confidentiality, including how and if this adds or detracts from the credibility of research, whose interests are served in the process, and how the harms from which anonymity and confidentiality are supposed to protect participants are conceptualised. We conclude with some ideas concerning navigating the way through anonymity and confidentiality in critical research upon which each chapter in this section then builds.

## Purposes of Anonymity and Confidentiality

Novak (2014) points out that anonymity is a complex term. It can apply to the legal name of a person, as well as to the possibility of locating that person based on a number of indicators. Anonymity is applicable at the individual

level but also in terms of geography and at the level of the collective, as in organisations, schools, villages, NGOs, government departments, and communities. *The Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Department of Health, Education and Welfare (DHEW), 1978), which is often considered a founding document on research involving human participants, sees anonymity, confidentiality, and privacy as the means by which researchers can maximise possible benefits and minimise possible harms. The harms, in this instance, include negative emotional outcomes, stigma, retribution by a third party, damage to reputation of individual or organisation, or withdrawal of support by organisations, funders, family members, or friends.

Anonymity is closely related to confidentiality in that anonymising data assists in confidentiality. The two are not identical, however. Confidentiality implies that researchers will not share identifiable personal information with others. It is important for researchers to understand the limits of confidentiality. For example, in most countries, if researchers learn of instances of child abuse they must report it. Likewise, if researchers encounter other illegal activities or crimes, they may be subpoenaed to reveal their sources (Haggerty, 2004). Researchers need to weigh these formal requirements against their sense of ethical duty in extreme cases. Ashdown et al. (2018, this section), for example, provide a rationale for preserving anonymity in a project in which illegal activity may well be described by participants (such illegal activity may have been previously reported or not, but either way ethical questions arise for researchers). Wiles, Crow, Heath, and Charles (2008) found that researchers reported feeling personally compelled to break confidentiality when participants were at risk of harm but not in cases of involvement in illegal activity.

All the authors in this section acknowledge the necessity of considering seriously the potential of harm upon participants in the process of gathering data and dissemination of research. However, they challenge researchers to expand the intertwined notions of harm and ethics by taking into consideration the limitations of promised anonymity and by seriously reflecting upon both the limitations and potential offered by allowing participants to share their identities when researchers are committed to a critical research agenda.

## The Limits of Anonymity

A number of researchers (e.g., Saunders, Kitzinger, & Kitzinger, 2014; van den Hoonaard, 2003; Walford, 2005) argue that guaranteeing complete anonymity to participants can be an unachievable goal, particularly in qualitative

and ethnographic research. At a basic level, researchers on the team, particularly those who conduct interviews or interact with the participants in some way, will usually know the identities of the participants in any case. This means that what Tolich (2004) calls internal confidentiality among those involved in the research is rarely possible.

The more pertinent measure of anonymity, however, is that which applies to persons other than the primary researchers. Once again, there are challenges. In their chapter, Marx and Macleod (2018, this section) draw attention to the use of pseudonyms as a conventional method of maintaining anonymity. After facing the challenges of getting institutional approval to allow women participants who had left violent relationships to reveal their identity should they wish, they (the researchers) opted, in a new study of queer performances, to use each participant's stage name instead. This decision entailed a degree of possible identification within the queer community of that city. Naidu (2018, this section) reflects on engaging community groups and NGOs that may be easily identifiable. Similarly, in one case study, Ashdown et al. (2018, this section) work with participants drawn from a residential therapeutic community for men with a history of criminal offending. In both cases, people who live in the communities in which the research was conducted may be able to recognise the participants and the sites of the study. Moreover, the growth of internet technologies has meant that protecting the identity of participants is an even bigger challenge than it has been previously (Novak, 2014), an issue reflected on by Naidu (2018, this section) in discussing the inclusion of a participant's published poetry.

The requirement in qualitative research, in particular critical research, to provide significant contextual information so that the findings may be read in context means that readers may be able to locate the study simply from descriptions of the site, even if pseudonyms are in place for both the individuals and the organisations featured in the research (Tilley & Woodthorpe, 2011). This is exacerbated by the fact that academics tend to use research sites that are geographically convenient, so readers may guess the location of the study and also individuals who are part of the study (Walford, 2005).

Finally, there is a growing emphasis on the need to report to funders which raises questions regarding the anonymity and confidentiality of participants, especially if the funders are also the organisations in which the study took place. In contrast to this, Rucell (2018, this section) suggests the need to re-think one's commitment to confidentiality and anonymity when researchers encounter incidents that harm participants in a given organisation. Drawing from examples in which there may be unreported incidents of violence, she asks whether blanket anonymisation makes research data 'impotent', which in

turn may weaken researchers' contribution to public interest. In such cases, the individual focus of harm prevention may be at odds with public transparency.

Some researchers have gone so far as to suggest that anonymity is a nearly impossible ideal. Van den Hoonaard (2003) maintains that anonymity is only really maintained through 'the natural accretions of daily life, the underuse of data, and the remoteness of place and time between the gathering-data stage and the eventual publications of findings' (p. 141). Stein (2010) reaches the same conclusion, questioning whose interests are served in the quest of anonymity.

## Identifying Participants

A number of chapters in this section reflect on the challenges that occur to anonymity requirements when participants themselves insist on not using pseudonyms. Naidu (2018, this section) relates how in a therapeutic case study the participant wanted her name associated with the poetry that she produced in the sessions. Similarly, Rice and Mykitiuk (2018, this section) grapple with the question of the intellectual property rights of participants who produce art and performances as part of their research study.

Both cases highlight the importance of voice when thinking about anonymity. Voice, ownership of data, and intellectual property are key components for consideration in anonymising data. Voice refers to the possibility of people who, through a range of power relations that serve to marginalise them in society, are silenced in particular spaces. Rice and Mykitiuk (2018, this section) suggest that anonymity may shore up the distinctions between researcher and those who are researched in terms of voice.

Concerns over data ownership emerge particularly in in-depth (auto)biographical life story, oral history, and narrative work (Tilley & Woodthorpe, 2011). As people delve into their own or their community's histories, the question emerges of who owns these data and who determines how they are used. This applies not only to contemporary accounts, however, but also to archives in which records of people's lives are held. Wright and Saucier (2012), for example, ask, 'Is the concern over confidentiality giving way to a new emphasis on returning names (and agency) to vulnerable groups in the past [who have passed away]?' (p. 65). Assigning a name to a participant may, in part, be a form of assigning partial authorship. At the same time, researchers need to remain critical of how the processes of 'giving voice' and 'returning'

are inscribed with power relations that may reinforce the status quo of particular power relations.

This is particularly significant in contexts wherein researchers engage with communities marked by colonialism. Indeed, Ashdown et al. (2018, this section) suggest that individualised notions of concealing identities reveal cultural bias. In their engagement with Māori participants, they point out that naming individuals is relevant to indigenous peoples due to shared goals of self-determination. In such a context, naming the individual is tied to a larger social and political project in a site where communities have experienced dispossession. For the authors, concern with non-maleficence may in turn lead to a failure to recognise the contribution of participants.

Similarly, Marx and Macleod (2018, this section) point to the complexities of concealing the identities of queer participants and women who have experienced intimate partner violence. Both groups of participants often contend with invisibility and masking their identities may equate to a form of 'going back to the closet' in cases in which participants may have had little opportunity to speak. Remaining cognisant of the complications of affording spaces for voice, the authors point out the need to reflect on how masking identities can both promote and undermine ethical practice from feminist and queer perspectives. For Rice and Mykitiuk (2018, this section), negotiating visibility is critical when adopting a disability justice perspective. In their chapter, they draw on cases that make use of art-based mediums that in turn transgress the boundaries of anonymity and privacy. They reflect on how non-normatively abled participants contend with the entwined legacies of being put on display or being hidden away both in academic research and beyond, as well as the manner in which participants are often reduced to parts of their bodies and minds. Assigning authorship to creative output, which entails revealing identities, speaks to such forms of representation.

## Difficult Questions Regarding Anonymity and Confidentiality

In the light of the issues discussed in this section, researchers increasingly question the stock ethics committee requirement that researchers should outline *what* measures are put in place to ensure anonymity and confidentiality. Further questions that should be posed are: firstly, *whether*, and under what circumstances, measures need to be put in place and, secondly, whether a case can be made for participants to refuse anonymity and confidentiality. Giordano,

O'Reilly, Taylor, and Dogra (2007), in their analysis of the ethical guidelines of the World Medical Association, British Psychological Society, British Association for Counselling and Psychotherapy, and the American Anthropology Association, indicate that these bodies do not *impose* the requirement that researchers should protect the identity of their research participants. In the light of this position, it is imperative that critical researchers engage in reflection on the various issues that attend to identity management in research. In the following, we speak to a number of these issues, including credibility of the research, whose interests are served, and conceptualisations of harms.

Lincoln and Guba (1985) established credibility, the confidence one can have in the 'truth' of the findings or the equivalent of internal validity, as an important component of qualitative research. The question of whether anonymity adds to or subtracts from credibility has received some attention. Giordano et al. (2007) argue that anonymity assists credibility. On the one hand, participants may be more honest in expressing themselves, especially about sensitive personal matters, if they know that what they say cannot be traced to themselves. On the other hand, making participants' identities known may encourage accountability for the information shared. As Lelkes, Krosnick, Marx, Judd, and Park (2012) indicate, however, this accountability may be accompanied by a motivation to distort reports in socially desirable directions.

Anonymity is supposed to protect participants from potential harms associated with being part of the research. A number of researchers have, however, questioned whose interests are really served in anonymising participants. In this section, Rucell (2018) indicates how anonymity provisions may be put in place to protect the institution from legal action. Similarly, Walford (2005) suggests that the promise of anonymity forms part of researchers' access strategy, particularly in institutions where there is much external scrutiny and evaluation. Novak (2014) indicates that anonymity can act as a licence for researchers to interpret the data in ways that 'free(s) them from the responsibilities of truth telling and accuracy' (p. 69). Moreover, in cases in which participants have produced artistic work as part of the research, such as in Rice's and Mykitiuk's research (2018, this section), by not crediting the participants' work, only researchers' CVs are enhanced. The same argument can be applied to any intellectual output of research on which the researchers are authors whilst the participants go unacknowledged when anonymity is imposed.

In terms of the usability of the findings, Walford (2005) argues that failing to name sites of research gives the results a spurious sheen of generalisability. While Rucell (2018, this section) is concerned with negative effects when

individuals and organisations are not transparent, Tilley and Woodthorpe (2011) believe that where organisations are doing innovative work, and may provide examples of good practice to others, anonymising the sites decreases the usability of these good practices. Consequently, these are not beneficial to the sector within which the research was conducted either for the reputation and prestige of the specific organisation or for the sector in general.

For the most part, researchers and institutional ethics committees define questions of harms, non-maleficence, and beneficence prior to entry into the field. Seldom considered is how participants may understand potential harms and the measures needed to protect them from these harms. For Marx and Macleod (2018, this section) working within a feminist and queer perspective means being attendant to how such procedures may limit participants' involvement in setting a research agenda.

How harms are conceptualised, however, is also a matter of contention. As Rucell (2018, this section) points out, harms are generally forecast based on the imaginations of reviewers and researchers rather than on sound evidence bases. Sikweyiya and Jewkes' (2011) work is pertinent in this regard. They pose the question: does research on gender-based violence (GBV) pose greater than minimal risk of harm to researchers and participants? This is an important question in the light of the fact that ethics committees frequently assume there are high risks (e.g., secondary trauma and/or increased violence against the victim) associated with conducting GBV research. Their conclusion, after interviewing 12 experienced GBV researchers from various countries as well as a desk review, is that the idea that GBV studies carry more than minimal risks of harm when precautions are followed is speculative rather than evidence-based. Furthermore, harms, as highlighted by Ashdown et al. (2018, this section), are generally considered at an individual level. When researchers view harms at a collective level, a different picture may emerge in relation to the harms enacted upon communities that are rendered either known or anonymised.

## **What Are the Issues that Need to Be Considered?**

If an automatic assumption of the provision of anonymity and confidentiality is removed, what are the issues that researchers need to consider in order to act in an ethical fashion? In the following, we discuss how the epistemological and methodological stances of the research make a difference. We speak to the key question of 'vulnerability' and what that means for thinking through levels of anonymisation.



The authors featured in this section do not see research as a neutral process of knowledge production but rather as an intervention in the world. It is precisely this point that underpins these authors' uneasiness about the standard requirements of anonymity and confidentiality. Working from disability justice, feminist, queer, indigenist, and social justice perspectives, these authors foreground the power relations that render particular people (often called 'vulnerable') invisible and silent or, alternatively, exotic and other. Their critical approach to research renders it impossible for them to ignore the implications reflecting on the implications of their research for their participants' agency and voice.

Particular methodological approaches also pose challenges to anonymity. Oral history, Le Roux (2015) indicates, 'sets out to contribute to historical understanding, validate respondents' lives, contribute to democracy and facilitate socio-political transformation' (p. 552). Enforcing anonymity denigrates respondents in this case. Longitudinal studies, which involve extended timeframes and intensive research relationships, pose challenges to the possibility of anonymity (Taylor, 2015). Action research, participatory research, and research collaborations also test the boundaries of anonymity and confidentiality. As pointed out by Reid and Brief (2009), in community-based research, confidentiality means that participants have no assurance that their involvement may lead to social change.

The notion of 'vulnerability' is key in the application of anonymity and questions of participation, in research. Vulnerability can be thought of in terms of reduced autonomy, such as in the case of children and prisoners or in terms of susceptibility to emotional, physical, or social harm. Researchers who study 'vulnerable' populations are generally asked for significant detail in their ethics protocols regarding how they will manage the risk of harm, including through the measures of anonymity and confidentiality. The logic in this instance is that 'vulnerable' populations are in need of more 'protection' than otherwise would be the case and that greater care needs to be taken to ensure that their rights to privacy and the principle of non-maleficence are maintained.

Marx and Macleod (2018, this section) point out, however, that the notion of 'vulnerability' is a contested one. Under which circumstances and to what extent a person, group of people, or community are considered 'vulnerable' is a matter of historical and locational variation. The notion of 'vulnerability', in addition, homogenises the identity of the people spoken about and leaves aside questions of agency, resilience, alternative identities, and actions. It focuses attention on the person who is 'vulnerable', rather than on the social circumstances that construct and maintain that position. In addition, people

who otherwise would not be considered vulnerable may experience vulnerable times, such as bereavement, birth in the family, and retrenchment (Tolich, 2004).

## Processes

If anonymity and confidentiality are not considered standard responses at the outset of a research project, if researchers are not obliged to fight for exceptions concerning anonymity, and if researchers are not expected to deal with the fall-out from unrealistic promises of anonymity, what processes need to be put in place to ensure ethical research conduct? In the following, we provide some tentative suggestions. As with most ethical principles and processes, however, these are generally refined through the test of application and time.

Various scenarios are possible in thinking through the questions of anonymity and confidentiality in research: (1) researchers set out at the beginning to allow participants to manage their own identity in the research process and outputs; this is included up front in the research proposal and ethics protocol; (2) researchers, with motivations based on vulnerability and potential harm, decide which participants/groups of participants should be enabled to manage their own identity in the research; (3) researchers retain the standard options of anonymity and confidentiality, but, during the process, participants insist on not remaining anonymous. In addition, there are various levels of anonymity in each of these scenarios (as indicated earlier) that require thought. In the following, we deal specifically with option (1) in terms of consent processes.

Researchers are tasked with obtaining informed consent from participants prior to collecting data. If identity management forms part of this process, as indicated in option (1), this opens up the question of how to navigate this terrain. Providing potential participants with the choice of how to be named is not a simple one. Consideration of what information participants would need to empower them to make informed choices is essential (Giordano et al., 2007). Researchers would need to think through the possible consequences for participants, organisations, and locations that are named, of potentially both positive and negative consequences. Most of these potential consequences will be specific to the particular research. It is essential, however, to consider how one named person's disclosure might impinge on the autonomy of others and on their right to confidentiality.

In terms of the information supplied to potential participants, this again will depend on the study. It would be useful to consider a few generic pointers:

- If participants are not co-researchers, or are not provided with the possibility of vetoing particular ways of writing about them, then they need to understand that how their views, opinions, and/or relevant data are presented in final form might not be what they had anticipated. They need to know that the autonomy of the researcher means that s/he has some discretionary space for interpretation of data based on the epistemological approach taken.
- Once the participants' identity appears in print or online, it cannot be retracted.
- While researchers may target particular audiences in publishing their work, there is no guarantee of who will read the work or in what context.
- Not all contributions will feature in the final report. This does not diminish the importance of their participation as all the material that was collected will have contributed to the patterns that are discerned.

It is also important to consider how this information is presented to participants and how options are negotiated. Our suggestions are:

- Researchers need to enter into careful dialogue concerning any potential positive or negative consequences (some of which only the participants would know), which is then later recorded (e.g., on a signed form or other written confirmation).
- Researchers could consider ongoing consent options. This allows for participants to change his/her/their anonymity/confidentiality status without changing his/her/their participation in research and/or services offered if the research is about services.
- Researchers may also pilot consent forms to iron out any difficulties that might arise.

When critical epistemologies and methodologies are novel to ethics committees, the standard protocols may be enforced more than is usual and the risk of rejection may be high as is evidenced by Rice and Mykitiuk (2018, this section) as well as by Marx and Macleod (2018, this section). Authors in this section suggest a range of ways in which critical research ethics protocols may improve upon traction, in particular regarding questions of anonymity, confidentiality, and safety. Rice and Mykitiuk (2018, this section) contend that it is contingent upon researchers to introduce critical theory into the writing of ethics protocols. In other words, researchers need

to do the work of convincing reviewers through theoretical argumentation. While this is certainly a productive avenue, teachers of critical theory know that a single reading is seldom sufficient to induct readers into the complexities of critical theory or ethics. Placing the burden on critical researchers of convincing ethics committees of the merits of critical research is inequitable given the ease with which non-critical methods, particularly experimentation, are readily accepted and perpetuated. Marx and Macleod (2018, this section) go further, suggesting that ethics committees should include reviewers who are au fait with critical theory and are, hence, able to engage with the nuances required of thinking through the ethical complications that may arise.

## Conclusion

Students are often introduced to the histories of unethical research studies that involved harmful participation. Guidelines such as the Belmont Report emerged in the context of such legacies in human research. As a result, ethics protocols require that researchers indicate an awareness of potential harm prior to undertaking fieldwork. Protecting the identities of participants is one of the key requirements in standard protocols. This section presents a number of cases in which researchers outline the limits imposed by automatic anonymisation of participants and question the effects of confidentiality. While a few cases draw attention to the difficulties in ensuring complete anonymity, a number of authors also consider what happens when identification may be desired or welcomed. For researchers working from indigenist, feminist, queer, and dis-ableist perspectives, visibility presents both challenges and opportunities when participants have experienced historically, and continue to experience, a silencing of narratives. The chapters in this section, therefore, point to the necessity of continually re-thinking and revising how researchers construe ethical practices around anonymity and confidentiality within institutions that set parameters as well as for researchers who are actively engaged in fieldwork.

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